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ABSTRACT

This document presents a training manual to help caregivers who provide care to older family members and friends at home. The program, which offers a practical approach to caregiving and a realistic view of the aging process, is intended to clarify the problems confronting caregivers of older people, serve as a basic source manual for training current and future caregivers of older people, and provide resource information that can be continually changed and updated to meet the needs of caregivers throughout Rhode Island. Designed to be used as part of a group teaching format, this manual is divided into five parts which can be presented in five 4-hour sessions. Included is the basic information needed to conduct each session, as well as group exercises and questions for discussion. Part I provides an introduction to aging and caregiving. Part II focuses on communication. Part III looks at the emotional and psychological aspects of aging and caring, including reactions to change and loss, and talking about death. Part IV discusses physical and medical concerns, normal aging, how an older person should be evaluated, functional abilities, and common medical problems (memory loss/confusion, falls, incontinence, and managing medications). Part V suggests techniques for coping with caregiving. A personal care guide and a variety of handouts for caregivers are appended. (NB)

R.I. CAREGIVERS

Caring: A Training Program for Family Caregivers

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We have compiled this manual under a grant from the Administration on Aging, Title IV of the Older American's Act and the Rhode Island Department of Elderly Affairs. The Rhode Island Department of Elderly Affairs wrote the grant in recognition of the valuable role played by family members, friends, and supportive persons who are providing daily care to older Americans within our communities. It is our intent to help caregivers in their role and to lighten the burdens of caring for semi-independent and dependent older people. We have designed the manual to be used as part of group teaching, offering information about caring for frail older people and support for you, the caregiver.

An Advisory Committee (see Appendix), representing a wide range of agencies throughout the state, has collaborated on this project. We wish to extend special acknowledgments to Mrs. Adelaide Luber, Director of the Department of Elderly Affairs, to Mr. Anthony Zompa and Ms. Kathleen McKeon of the Department's Division of Planning, authors of the grant, for their sustained support of the project. And a very special thanks to Dr. Donna Murphy for her valuable time, input, and assistance during the development of this manual.

Special acknowledgment goes to the publication *PRACTICAL HELP*, prepared by the Program Development Unit of the New York State Officer for the aging and upon which Rhode Island Caregivers is based. Mr. Gary Brice introduced *PRACTICAL HELP* and the *CARERS* program to Rhode Island, sparking the imagination of those who have

brought the subject thus far. Thanks also to Dr. Robert Marshall of the Rhode Island Department of Health, who has remained committed to bringing such a program to Rhode Island.

This manual was compiled by Brenda Pukas RN, FNP, Project Coordinator, Private Sector Discharge Support Project.

Thanks goes to Mrs. Nancy Ridley, Personnel Director at Metropolitan Life and to Mr. Robert M. Proulx, Department of Human Life Resources, Ami Hoechst Corporation, for their cooperation.

We believe that information, guidance, and peer support will help caregivers be better prepared for their present and future caregiving roles. That is what this manual is all about.

TO THE CAREGIVER

We have developed this training program for you, because you, as a caregiver, hold a very important role in our society. You, and others like you, provide about 80% of the care to our nation's frail, older population. For many of you, your caregiving efforts exceed the demands of most full-time jobs. For those of you who also manage a household or work outside the home, caregiving might be your second "full-time job."

Whether you provide care to an older person several hours a week, or 24 hours a day, your task is a tough one. The physical and emotional demands of caregiving can be exhausting. We believe you need all the information and support you can get to help you sustain your very important caregiving efforts. We hope that with appropriate information and support, you will be able to experience many of the joys and rewards that come from caring for others.

This training program consists of five parts or sessions designed to give you a better understanding of the aging process and provide practical suggestions for caregiving. Each part focuses on a specific topic. Your group leader will present basic information on the topic and will head the group in informal discussion and group exercises.

We think you will get the most out of these sessions by discussing your experiences with others. Sharing your feelings, questions, hopes, and fears can truly make a difference for others in your group and in the lives of those for whom we care.

TO THE TRAINER

This training program will assist people who provide care to older family members and friends at home. The program offers a practical approach to caregiving and a realistic view of the aging process. The manual is a learning tool to be used as part of the program.

It is a survey of broad topics and problems that confront caregivers. It is designed to help family members, friends, or neighbors who are caregivers or who will be at some future time. It is also for older people who want to learn more about themselves, their peers, and the aging process.

This program is intended to:

1. Clarify the problems confronting caregivers of older people.

2. Serve as a basic source manual for training current and future caregivers of older people.

3. Provide resource information that can be continually changed and updated to meet the needs of caregivers throughout the various communities of Rhode Island.

The training program consists of five parts which can be presented in five sessions of about four hours. The topics may be introduced at shorter meetings or workshops in the workplace or other social settings. This manual contains the basic information needed to conduct each session, as well as group exercises and questions for discussion. Any part of the manual can be reproduced

for handouts. The session can be led by professionals or lay persons - by those who have experience in training caregivers or by those who are new to this leadership role. We recommend working in groups of 10 to 15 people. A comfortable and informal setting will promote meaningful interaction among participants. A blackboard or flipchart might be useful for recording shared experiences.

As a group leader you will want to supplement the manual with materials of your choice. It is anticipated that updated articles of interest will be added to the basic topics covered herein. Be prepared to share your own caregiving experiences. If you would like to learn more about aging and caregiving, see the list of recommended books in the Appendix. Good luck!

Part I

Aging and Caring

Concepts of Aging and Caregiving

What Caregiving Means to the Adult Child

INTRODUCTION: AGING AND CARING

The Concepts of Aging and Caregiving.

Each individual must face the aging process. As the years pass, the body grows older, the emotions and feelings, however, do not drastically change. We can all feel young or old despite our age and depending upon the circumstances in which we live. It is essential in viewing the aging population that we focus on the individual as a person - a person with rights and responsibilities.

To grow old gracefully is an art. It is the challenge of accepting each day and each year as it comes and reacting to the strengths and limitations of aging, in a graceful manner. In growing up, children must learn to accept added responsibility. In growing older, each person must be content to relinquish some responsibility to others yet be responsible for himself.

Caregiving is as old as civilization. Caring and establishing relationships are part of living in society. Today the concept of caregiving has taken on added meaning. Many of us must be prepared to care for the frail elderly in our family.

Aging is a lifelong process. We have hundreds, maybe thousands of books about early childhood and adolescence. Not very long ago it was assumed that a person went through all of the early growth stages, became an adult at about age 21, and that was the end of the growth and development. We now know better. In recent years we have learned about such things as "mid-life crisis,"

"passages," and "stages of later development." Studies of the adult years have shown that everyone continues to develop and change throughout the life cycle.

Just as no two individuals are alike during the early stages of growth and development, they are not alike during the later stages. We must look at each person as an individual. Older people have lifelong histories of personal growth and development. They have established unique styles of handling work and family responsibilities. This individuality is brought along into one's later years. Uniqueness is important - important to the older person and to the caregiver. Aging comes on slowly, insidiously, over a long period of time and then suddenly catches us unaware. It is important to remember that it happens to all of us without exception.

A Look at the Growth in the Older Population

Nationwide, about 12 percent of the population is age 65 or older - this means about 24 million people. If we look at those older than 55 years, we find 20 percent or 44 million people. Rhode Island has the second highest percentage of older people in the nation, second only to Florida. We have a significant number of three or four generation families. Since this is such a new phenomenon, we have very few role models to follow. Families today must construct new ways to help and care for each other. We must learn how to cope with the demands brought about by the fact that more of us are living longer.

Causes of death among older people are generally similar to those of the population as a whole. The leading causes of death are heart disease, cancer, stroke, influenza/pneumonia. Older people use more health care services than younger people and they have more chronic illnesses that younger age groups. Although chronic illness causes some limitation in activities, most older people are self-sufficient and able to function on their own with minimal assistance. Only 5% of the over 65 population is in nursing homes. That means that 95% of older people are living on their own or with families in the community. Those who do need help tend to be among the very old. Look at the statistics:

65 - 74 years old	88% have no disability
75 - 84 years old	74% have no disability
88 - up	29% have no disability

Of those 88 years and older, less than 20% are confined to bed. Of that same group, almost two-thirds need NO HELP at all with the activities of daily living.

The concept of the "sandwich generation" is a relatively new phenomenon. It is useful in describing the generation which finds itself in the middle of multiple caregiving responsibilities. In addition to caring for an older relative or friend, the individual of the sandwich generation is: 1} still raising his/her own children, or partially responsible for them, and 2} leading his/her own adult life, which usually involves work, social, cultural, and civic activities. Adult daughters bear the major caregiving responsibilities, often assuming the care of their own parents and also sharing in the care of their in-laws as well.

What Caregiving Means to Adult Children

As long as our parents remain self-reliant and independent, continuing their life as they always have, children usually feel comfortable and continue whatever style of interaction has been established historically within the family. When the amount of independence changes, the relationship often changes. Adult children may be fearful of the change, frustrated by events and find it difficult to face the declining condition of their parents. As a result, adult children may actually avoid contact with the aging parent, creating further feelings of frustration, guilt and fear on the part of both parents and adult children.

Aging parents occasionally place unreasonable demands on the adult child. This can occur for many reasons: fear of being alone and helpless, fear of desertion, or fear of death. Caregivers at the same time often place unreasonable demands upon themselves. This happens for a number or reasons. Among the complex feelings adult children may have for their parents are: love, fear of physical and mental decline in the parent, responsibility, sadness, helplessness, hostility, resentment, guilt, and anger. In other words, adult children feel the entire gamut of possible emotions.

Often adult children are reluctant to express their feelings toward their parents, especially if they think their feelings are negative. Negative feelings often surface in the event of an aging parent's declining health and functional ability. It is important to recognize that all feelings are normal reactions to stressful situations. It is only when recognized and expressed that these

feelings can be put into perspective. Counseling or support groups may be helpful in assisting caregivers to understand and accept their emotions toward persons receiving care as well as to understand and accept their own emotional needs. Professional counseling or therapy may be needed once strong feelings, especially hostile and negative feelings, are recognized.

Hidden benefits often arise at a time of crisis. While recognizing the problems and difficulties that occur with advancing age, declining health and functional ability, these problems often bring out the best in every member of the family, drawing them closer together. Good feeling and an increased depth of caring and understanding occurs when the younger generation rallies to help the older. All generations benefit from working together to solve difficult and painful problems. This is especially true when a pattern of closer relationships is set for the future.

Aging and caregiving are both complex issues. We can begin to understand their importance by clarifying our own ideas about these concepts.

Part II

Communications

Communication Is So Important

Sensory Losses and Communication

Part I: COMMUNICATION

Communication Is So Important!

We make contact with each other by communicating. Through communication we reach out to others, receive from others, clarify our thoughts and feelings to ourselves, and continue to learn throughout the lifespan. Indeed communication, especially speaking, listening, and thinking, is the very thing that separates man from animals. When communication is blocked, human contact is diminished and the quality of life becomes lessened.

We can talk to someone and not be heard. We can hear someone and not listen. We can try to reach someone by touch and not be felt. Communication is a complex transaction. It is not merely verbal, explicit, and intentional transmission of messages, but includes all those processes by which people influence one another.

Communicating with oneself helps organize thoughts and feelings, helps identify personal needs, and supplies information to better understand oneself. Communicating with others allows these thoughts and feelings to be shared, challenged, and revised. Because communication is so important both for personal as well as interpersonal development, we must do everything possible to preserve and foster it in later life.

Sensory Losses and Communication

Opportunities for positive communications are vital to a person's sense of self-worth and importance. Often, aging brings changes in vision, hearing, and speech, which can make communication difficult. The older person may feel self-conscious, angry, and depressed, he/she may also withdraw or seem uninterested in socializing due to feelings produced by some of these changes. It is important to recognize sensory losses and find ways to adapt to these changes with the older person for whom you are caring.

We rely on our sensory organs to communicate with others and relate to our environment. Senses diminish with age often causing a decrease in communication skills and decline in interactions with others. Some of the general sensory deprivations are:

Vision - eyes need more time to adapt to light and darkness; lenses yellow, clouding vision and making it difficult to distinguish colors.

Hearing - less able to hear high pitched sounds; difficulty discriminating between two sounds; losses may be gradual; may result in isolation and/or paranoia because of not hearing what is going on around one.

Taste - number of taste buds decline; ability to taste sugar and salt declines.

Smell - declines; may be hazardous if unable to detect odors of gas and smoke; may contribute to loss of interest in food.

Touch - less resistant to temperature change, may not feel heat and/or cold.

Compensating for sensory changes and losses helps to maintain a sense of independence and increase the sense of self-worth and dignity in the older adult. Older adults have acquired a lifetime of experiences that make them unique individuals. Discussing life experiences is a good topic around which to communicate with older people. Life review helps people to evaluate their past and come to terms with the present. An effective listener will express genuine interest, listen empathetically, and offer opportunities to help the older person express himself/herself despite sensory losses.

Life review, or reminiscing, is an effective way of stimulating memory and emotions. Reliving past joys and sorrows helps communication in the present. Family members and caregivers can suggest a variety of activities which emphasize the value and uniqueness of the older person's life.

People who are experiencing a moderate to severe degree of memory loss and confusion present special communication challenges to the caregiver. Reality orientation is a rehabilitative

technique which provides opportunities for the older adult to gain some orientation and become more self-directing.

The way in which you do reality orientation is to talk to the individual about where they are, what they are doing, what is going on around them, who is participating in their lives. Conversation should include time, dates, names of people, what the older person has been doing, current events, etc.. Aids that are helpful are: a calendar, a clock, newspapers, magazines, pictures of family members, and familiar belongings. Aids should be bright, colorful, easy to see, and to read.

Do not become condescending or treat the older person as a child. When providing continual information and environmental aids for reality orientation, remember to be patient, repeat directions frequently, and confirm correct responses. Continuity and consistency are the keys to successful reality orientation.

Part III

Emotional and Psychological Aspects

Reactions To Change And Loss

Talking About Death

Part III: EMOTIONAL/PSYCHOLOGICAL IMPLICATIONS OF AGING

Understanding Emotional Needs

Closeness to others, whether it is physical, intellectual, or emotional is a basic human need. To feel close to another, to feel love and to love, to experience friendship, to care and be cared about, all are feelings people need to experience. Relationships are built upon these feelings of security and safety.

Universal human needs are generally categorized into two groups: physical and psychological. Physical needs include hunger, thirst, activity, rest, sex, elimination, avoidance of pain, injury, and illness. Psychological needs include security, status, affections, esteem, affiliation, independence and dependence, achievement, and socialization. These needs are motivating forces that initiate behaviors to satisfy them. When certain needs are not satisfied, a person may become anxious, restless, and tense. A state of equilibrium is established when the need is satisfied.

Essentially, five levels of need must be satisfied to achieve and maintain a state of equilibrium. Those needs in order of priority (according to Maslow's hierarchy of needs) are:

1. Physical needs. (Hunger, thirst, elimination, sex, etc.)
2. The need for safety, security, stability, freedom from pain, threat or illness.
3. The need to belong and to be loved.
4. The need for recognition, of respect from others and self-esteem.

5. The need for self-actualization, or the need to grow, develop, and realize one's highest level of potential.

These needs hold true regardless of age. They apply to older people as well as younger people. Older people's desire to be physically and socially independent, to have a sense of purpose, self-confidence, and self-esteem are just as important as health care needs.

At times it may be difficult to determine how to meet these needs. Assistive devices may be required to help older people maintain the highest possible level of independence and mobility. Assistive devices include: canes, walkers, wheelchairs, emergency response systems, etc. Older people may resist using assistive devices, feeling they are a visible sign of dependency. It is important to present the more positive viewpoint - assistive devices of all kinds help one to do more, to be more active and independent.

Understanding Change and Loss in Later Life

During no other period in life is one confronted with so much change or loss than during later life.

Changes in WORK, STATUS, INCOME, VISION, HEARING, and MOBILITY, SENSORY LOSS and DEATH of a spouse or friend are some of the losses occurring in later life. These changes can lead to social isolation, loss of independence, power and roles, all of which can affect an older person's sense of well-being and self-esteem.

For instance, retirement, particularly compulsory retirement, may take away not only a person's meaningful work role, but also his sense of purpose.

Older people have patterns of living, working, communicating, and socializing which may change with age. Their ability to cope with these changes depends upon a number of factors: their personalities, the stability of their marriages, their relationships with their children, their roots in the community, their financial security, and their attitudes towards age and death. To understand the effects of age-related changes on an older person's outlook on life, we must view life as a process of change. We must take into account not only physical changes that occur with age, but also the psychological, sociological, and spiritual changes that can occur. Each of us differs in how we age, as well as in how we adjust to all the changes inherent in aging.

Successful adjustment depends on how MUCH change we experience at the same time, how RAPIDLY the changes take place, how many SUPPORTS we have to rely on, and how well we have learned to cope in the past. These four factors greatly influence each individual's response to change and loss in later life. Some people adjust to change better than others. Most people who have been happy and learned to live fully earlier in life will, barring any unusual traumas, continue to do so into old age. Complications arise, however, when social supports that were relied on throughout the lifespan are no longer available.

Reactions to Change and Loss

Depression, anxiety, hypochrondriasis, psychosomatic disorders, alcoholism, and paranoias are psychological problems which can occur at any age. For older people, these difficulties may appear for the first time in response to a loss or other stressful change. Depression is prevalent among older people. Symptoms include sadness, insomnia, anorexia and weight loss, teariness, helplessness, lethargy, fatigue, slowed thoughts, and hypochondriasis.

The severity of depression may be related to life-long coping patterns, the abrupt or unexpected nature of the loss, and the number of losses experienced in a short span of time. The chief signal that professional help is needed may be the extent to which one's ordinary daily activities are neglected.

Problems resulting from depression can be very difficult for caregivers. The family may believe that their relative has undergone a real personality change. Shifts in personality often result from a person's efforts to cope with the social, physical, and psychological changes encountered in later life. It is normal to react emotionally to loss. Since losses appear more frequently in later life than at any other stage, guilt, anger, depression, fear, anxiety, and hopefully eventual acceptance can be anticipated. These emotions are normal, progressive stages of mourning. Some people remain in a constant state of mourning in an attempt to cope with one loss after another. This process of continual mourning may lead to feelings of

unresolved grief expressed through feelings of anger, despair, denial, and depression.

It is important to realize that mourners go through many different stages on their way to recovery. Some of those stages can be very difficult. Your mourning relative may be full of self-pity or anger, withdraw from you one week and accuse you of neglecting him/her the next week. These behaviors may be puzzling and burdensome, but should pass in time. Of course people do not react the same way to the same loss. What may be difficult for one may not be difficult for another. When older people are faced with a stressful situation, they draw on the experiences and resourceful capacities accumulated over a life time. They often react the same way they reacted to similar situations in the past.

Rage is a powerful emotion people can experience in response to loss. It is a reaction to a situation we feel is hopeless and cannot be changed. Rage differs from anger. Once anger is expressed, both tne anger and the situation can usually be dealt with. Rage behaviors may be upsetting for caregivers, but they are normal reactions and responses to many real life situations, especially to loss. The caregiver should seek professional help when the symptoms mentioned above last for a long time after a loss occurs and when the older person is unable to go about daily living because of these emotions.

Physical complaints, denial, stubbornness, selective memory, regression, projection, and reminiscence are behaviors that can be either negative or positive, depending upon the degree to which they are displayed. It is sometimes easier to condition yourself to

remember happier times than it is to have to face unpleasant circumstances of the present. When these behaviors become repetitive, extreme, and chronic, and are continually used to avoid reality, they become maladaptive. Our responsibility as caregivers is to understand the function of some behaviors we see in older people.

Older people's complaints may be based on diseases or conditions they have acquired. Occasionally, people have learned to express themselves or to relate to the world through complaining or displaying symptoms of illness. Chronic complaining without a demonstrable base is referred to as hypochondriasis. Caregivers and professionals must be careful not to label the complaining older person a hypochondriac and thereby miss important evidence of real illness or declining function.

Rigidity or stubborness can be another way of coping. Although many older people are agreeable and welcome change, others react very negatively to it and appear overly rigid and stubborn. Change brings additional stress, particularly when the change is unwelcome or many changes are taking place at the same time. But remember that people of all ages are often extremely resistant to change. It may only be more pronounced in older persons. Again, expressing symptoms of illness may be a method of resisting change or of coping with a stressful situation.

Occasionally the older person may fear that no one will be concerned about them if they appear too well and independent. Thus they persist in complaining about feeling poorly. This phenomenon has been observed in isolated rural areas where older persons have

become dependent on community caregivers. If this happens, caregivers must provide security and reassure the older person that he or she will not be deserted by those who are providing care.

Coming to Terms with Death and Dying

Death is not an easy topic for discussion. It makes many people uncomfortable. It is important for us to come to terms with our own feelings about death before we discuss it with the older person in our care.

Facing death is done in many ways, each person accepting it on his/her own terms, in his/her own time. Some theorists have described stages which all of us go through as we deal with death and dying. These stages may include denial, anger, bargaining, depression, and acceptance.

People who are dying often face numerous fears. They may feel alienated because friends and family may not come to visit. They feel alone. Older people need to know they will not be deserted. They need support from friends, family, church, and community agencies. Caregivers face fear and losses also.

All must face their own mortality. The caregiver faces the loss of the individual for whom he/she has cared. The separation of this relationship is painful. It will be permanent. The dying person has had to face multiple losses, and now faces the uknowns of death. The person is going to die and does not know what death will bring. Will it be painful? Will he/she be alone and forgotten? How will

the end come? These are just a few of the questions the dying person may ask himself.

Religion and faith are other components that many people hesitate to talk about. The beliefs that the older people have about an after life are all important. Very often it is the faith and religious views that sustain people who are dying and they want to talk about those views. Encourage them to talk about their faith, about death, and about any other feelings that they wish to share.

It is important that the dying person trust the caregiver. If you are unable to talk about the person's death and dying, allow the other person himself to initiate this conversation. If he/she states "I'm dying," ask why he/she feels that way. Don't immediately respond with "Oh, don't be silly, everything's fine." The individual may be aware of how ill he or she is without anyone else saying a word. Denying the situation does not make it better. You, the caregiver, may provide the only chance the dying person has to discuss important feelings.

Again, remember that everyone is different. Certain individuals or cultures may not accept a discussion of death. You know better than anyone what your loved one may or may not be willing to discuss. If he or she does want to discuss death, and you are unable to do so, then find someone else who can. Contact your community agencies and ask a social worker, trained volunteer, or clergyperson to help you. You will be doing a great service not only for the dying individual, but also for yourself.

Part IV

Physical And Medical Concerns

Normal Aging

Evaluating Older Persons

Functional Abilities

Common Medical Problems

Memory Loss/Confusion

Falls

Incontinence

Managing Medications

PHYSICAL ASPECTS OF AGING

Functional ability looks at both what an individual CAN and cannot do. The emphasis is placed purposely on what an individual CAN DO. Functional ability can be observed - a very important point; CHANGES IN FUNCTIONAL ABILITY can be seen by the caregiver or by anyone who is "tuned in" to observing functional ability.

The caregiver needs to know about normal aging and functional ability and how it relates to the individual receiving care. The caregiver can identify **changes** more easily and will know when to call the doctor by watching functional ability. The caregiver can also better care for the older person and feel more secure in that role, not wasting time and energy in needless worry. At the same the caregiver will know when to call for immediate attention.

Normal Aging vs. Disease

No one knows precisely what constitutes normal aging. Aging is not a disease; it is normal, slowly progressive decline in physiological function, often accompanied by certain problems and changes. Aging does not cause disease and disease does not cause aging. Disease can occur at the same time as aging. We do know the following things about aging. It is:

1. UNIVERSAL AND NORMAL. It occurs among all life forms and among all humans.
2. INTRINSIC. It is programmed into our cells.
3. IRREVERSIBLE.

4. VARIABLE. It occurs at different rates in specific organs of the body.

We still do not really know what causes aging. We do know that aging is a normal, gradual, developmental process that begins at birth and continues throughout life. Physical and psychological changes are a part of the normal growth process. Since we are all individuals, the rate at which our body ages and psychological feelings and changes occur are different for each of us.

Our bodies have an excess capacity to function, and we do not recognize losses until we have lost about 40% of functional ability. Thus the gradual decline in functional ability remains unrecognized until it suddenly becomes obvious that something has changed. The point at which we recognize a functional loss is called its threshold level. Gradually diminishing eye sight is a common example of decreasing functional ability. An example of excess capacity is having two lungs when one can meet our needs. We rely upon our functional reserve to carry us through accidents or illnesses. We are all happy to have excess capacity in times of trouble.

The threshold level is different for different individuals and depends on: 1) the rate of the decline, and 2) the level of performance required by a certain situation. "The critical difference, in fact the hallmark of aging, lies not in the resting level of performance but in how the organ (or organism) adapts to external stress." For example, an older person may have no difficulty walking daily at a leisurely pace, but become short of breath in an emergency when he/she must move more quickly. Researchers are studying older people for long periods of time and are finding that certain

functions actually increase with age, rather than decrease. Clearly there is a great deal of individual variation. The research is certain to give us new knowledge about aging. We encourage people to be as active as possible to maintain their highest level of physical health.

Common Medical Problems

Common problems of aging can be identified by a series of I's.

. . Immobility . . Isolation

. . Instability . . Inanition (malnutrition)

. . Incontinence . . Impecunity (inadequate finances)

. . Intellectual impairment . . Iatrogenesis*

. . Infection . . Insomnia

. . Impairment of vision . . Immune deficiency

. . Impairment of hearing . . Impotence (sexual dysfunction)

*Iatrogenesis means that the patient is made worse by treatment within the health care system. Common iatrogenic problems for the elderly include: bed rest, multiple medications, dependency, trauma, and confusion caused by being away from home and in a hospital. By far, the most serious problem for elderly people is BED REST. A very short time in bed results in significant functional loss. Bed rest should be limited to the shortest time possible.

Evaluating the Older Person

The caregiver can help the physician to evaluate the older patient by providing valuable information about the patient's

functional ability. The evaluation and diagnosis of an older person is a difficult and complex task, but one that is critically important to proper care of the older person.

Essential Aspects in the Evaluation include:

1. Identifying signs and symptoms of common physiological problems.

2. Assessing functional ability. Measures of functional ability important in determining overall health, well-being, and potential need for additional services for elderly persons.

Recognizing Signs and Symptoms

Signs and symptoms are changes in a person's appearance or function. They say that something is wrong. Signs and symptoms show problems which may require a call for help.

Here is a list of several areas of the body and specific signs and symptoms that mean something is wrong.

Skeletal and Muscular Systems: Swelling around joints or at any location on the body such as: arms, legs, feet, or hands. Swelling may be accompanied by shiny, red or hot areas, bruising of the skin, or whiteness in the skin. The individual may grimace as he or she moves and/or move very slowly. The person may experience loss of strength or restricted movement of a joint or body part, or express pain when the affected area is touched.

Skin: Color changes; swelling; changes of temperature (skin feels hot or cold); clammy or moist to the touch; patches of dryness, oiliness, scaliness, or discoloration; appearance of sores, wounds, lumps; markings such as moles or warts; odor, especially odors that seem offensive to the observer.

Hair: Noticeable changes in the hair; loss of hair; scaly, irritated or crusted scalp; oily, dry, brittle hair; infestations.

Circulatory System: Swelling of ankles and feet, blue or white color of the nailbed, lips, feet or hands; swelling or hard lumps in the nodes of the neck, armpits or groin; changes in the pulse rate - fast, slow, irregular, weak or strong.

Respiratory System: Changes in the rate of breathing, faster or slower; difficult, shallow or noisy breathing; coughing up sputum that is white, yellow, greenish, thick or liquid, bloody or that has an odor; stuffiness, dryness, bleeding, draining from the nose; soreness of the throat, swollen tonsils with red or white spots, difficulty swallowing.

Digestive System: Redness, swelling, white sores in the mouth or on tongue, coating of the tongue, sweet or foul odor to breath; cracks at the corner of the mouth; dry, cracked lips; signs of nausea or vomiting; poor appetite; refusing to eat; drinking large amounts of fluid; bloating or swelling of the stomach or intestines; passing gas by belching or via rectum (flatus); signs of pain or

cramping often noted by patient reaching for or holding stomach or abdomen. Diarrhea or constipation; stools that are hard, black, blood tinged, clay-colored, or with large amounts of mucus; signs of pain when moving bowels.

Nervous System: Change in cognitive level of consciousness; sleepiness, drowsiness, irritablility, slowness in reacting; dizziness, instability when walking; weakness or paralysis of any body part.

Reproductive System: Vaginal bleeding or discharge; resumption of periods after menopause; soreness in the genital area; lumps in or swelling of testicles; swelling, discharge from the penis; swelling or lumps in the breast of both men and women; changes in the contour of breasts; discharge from the nipples; changes in nipples (inversion when there was none before) for both men and women.

Urinary System: Frequent urination; urgency (unable to hold urine once a person feels urge to urinate); dribbling of urine; feeling the need to urinate immediately after urinating; urine that is dark, rusty, or red in color; urine that is cloudy.

Eyes: Sensitivity to light; change in appearance to bright, dull, glassy, pinpoint or dilated pupils; redness; discharge or watering eyes.

Ears: Pain, pulling at ears; discharge or drainage; loss of balance.

FUNCTIONAL ABILITIES

Functional ability is how able a person is to carry out activities of daily living. Functional ability refers to what a person **can do** even though he/she has medical problems. The doctor will do a complete and careful physical examination, obtain appropriate laboratory tests, and order any other diagnostic tests which are needed. The doctor can tell how the medical illness or condition effects the way the older person functions.

How well a person can or cannot function is the best test of how much help and what kind of help is needed in the home. Certain things in the home may be changed to keep the older person maintaining maximum functional ability.

MEMORY LOSS AND CONFUSION

About 5% of those over 65 years, and 20% of those 75 years, have some degree of clinically detectable impairment of cognitive function. In nursing homes, 50% of people over 65 years display cognitive impairment. A careful medical examination and evaluation must be done to clearly define the impairment of mental function.

It is important to notice changes in mental functioning or cognitive ability. Something may be happening (a disease process, for example) to the older person who was functioning very well and now is not. Although there are standards by which the provider will asses mental understanding, the best measure of mental functioning status is comparison with past performance. Caregivers can provide invaluable information if they have observed the older person's functional ability as they provide care and support.

Important imformation about mental or cognitive function can be obtained simply by observing and interacting with the older person for a short itme. While observing and interacting with the older person, ask yourself the following questions: Is the person alert? Does the person respond appropriately to questions? How is the person groomed? Are the clothes soiled? Is the person cooperative or distracted, agitated or inattentive? Is the person oriented to time, place, and situation? These simple measures of cognitive functioning give important clues to mental status.

Other questions which will give valuable information are: Is speech clear? Can the person read, understand, and write? Is there good general knowledge? Simple calculations and copying diagrams

are diagnostic tools used by physicians to assess more sensitive cognitive function. Judgment and insight are other important related parameters. The presence of bizarre ideas, incongruent thoughts and delusions may be present in older persons with cognitive impairment. **Depression** and **emotional lability** (up and down mood swings) commonly occur in older persons with cognitive impairment.

Old age alone does not cause impairment of cognitive function of sufficient severity to render an individual dysfunctional. Cognitive impairment can be broadly characterized into three groups:

1. Acute disorders, usually associated with acute illness, drugs, and environmental factors {i.e., delirium}.
2. More slowly progressive impairment of cognitive function, as seen in most dementias, amnestic syndromes, and benign senescent forgetfulness.
3. Impaired cognitive function associated with affective disorders and psychoses.

Delirium and Dementia

Delirium is an acute or subacute alteration in mental status especially common in the elderly. Key features of this disorder include:

- Clouding of state of consciousness
- Symptoms and signs developing over a short period of time
- Fluctuations of the symptoms and signs
- Improvement or normalization of mental function after the underlying condition has been appropriately treated

Some common causes of delirium are the following:

- Metabolic disorders • Infections • Fecal impaction
- Urinary retention • Intoxication • Stroke • Drugs
- Decreased cardiac output • Acute psychoses • Many others

Dementia is a clinical syndrome involving loss of intellectual functions and memory of sufficient severity to cause dysfunction in daily living. Key features of this disorder include:

- A gradual beginning
- No clouding of consciousness
- Relatedness of an organic factor.

Depression

Depression is common among older persons. It may be associated with a treatable physical illness or be the presenting symptom of a mental illness. The fact that depression and physical illness often coexist sometimes causes treatable depressions to be overlooked. Neither the depression nor the physical disease gets proper attention or treatment when this occurs.

Some of the signs and symptoms of depression are as follows: the person may look sad or appear unkempt when previously he/she has been neat and clean, or the person may show no emotion at all or have no energy and withdraw from all activities. It may be well to note that physical appearances can be deceiving. Aging changes as well as certain common medical conditions can lead to the appearance of depression even when there is none.

Numerous and unrelated physical complaints and symptoms can mask depression. The older person may feel that physical complaints are more acceptable than expressions of emotions. He or she may find it impossible to express feelings of sadness, guilt, or anger directly. The process of expressing emotions through physical complaints is called somatization.

Changes in sleep patterns, particularly insomnia, are associated with depression. Most important to remember is that signs and symptoms of depression are complex, complicated, and deceiving in the older person. This must always be kept in mind to avoid underreaction or overreaction to a diagnosis of depression in this age group.

FALLS

Falling is one of the most frightening things that can happen to an older person. Falls are the major cause of disability and often cause the older person to be hospitalized. Close to one-third of people over 65 years of age and living at home will suffer a fall each year. About 1 in 40 of those will be hospitalized. **Only about one-half of older persons hospitalized as the result of a fall will be alive one year later.**

The complications of falls are often devastating. The injury itself results in painful soft tissue injuries (bruises, abrasions, muscle strains and sprains, etc.). Fractures are common, occuring most often in the hip, femur, humerus, wrist, and ribs. An often overlocked complication of falls is subdural hematomas. Subdural hematomas result from injured vessels bleeding slowly into the subdural layer of the skull. The collection of blood occurs slowly and steadily over a period of days until the pressure created by the hematoma causes neurological symptoms. Neurological symptoms such as sleepiness, mood changes (agitation, irritability), confusion, and paralysis may not appear for many days after the fall. This is a very treatable condition, requiring prompt attention once it is recognized. Thus it is important not to forget about a fall even when there seem to be no immediate consequences. Other complications resulting from falls include:

- Hospitalization and complications of immobilization and iatrogenic illnesses.
- Disability - impaired mobility due to the injury.

- Impaired mobility from fear of additional falls, loss of self-confidence and restriction of ambulation imposed by caregivers or self-imposed as a safety measure.

- Risk of institutionalization - falls or the fear of falls often become the deciding factor to admit an eldery person into a nursing home.

- Death - as a result of the injury itself or complications from the fall and/or injury.

There are multiple and often interracting factors which cause falls among the older population. Age-related factors plus environmental factors together cause the vast majority of falls. Important age-related factors are:

Changes in postural control. Decreased awareness of where one's body parts are in relation to the whole, slower righting reflexes impairing the ability of the body to quickly "right" itself when it gets off balance, decreased muscle tone, increased postural sway, postural stooping and orthostatic hypotension (which is a drop in blood pressure when one changes position quickly, such as getting up from a chair).

Changes in gait. Not picking up one's feet as high, which causes tripping over door thresholds, bumps in the floor, or wrinkles in a rug. Men develop a flexed posture and wide-based, short-stepped gait while women develop a narrow-based, waddling gait.

Increased incidence of pathological conditions relating to stability. Degenerative joint disease, fractures of the hip and femur, residual effects of strokes, muscle weakness from disuse and deconditioning, peripheral neuropathy (decreased sensations in the hands and arms, feet and legs), deformities of the feet, impaired vision, impaired hearing, forgetfulness and confusion, and other specific diseases.

A doctor must carefully evaluate the older person who has had a fall. The doctor must try to determine the cause of the fall and whether or not an injury has been sustained. He or she must initiate the appropriate treatment for the injury or underlying disease or condition. The management of falls includes every effort to prevent another fall. Physical therapy, gait training, muscle strengthening exercises, and the use of assistive devices are some of the therapies of management. In addition, patient education can help to prevent both initial and recurrent falls. Caregivers can teach adaptive behaviors to the older person. For example: performing physical activities more slowly and carefully, rising from a lying to a sitting position slowly, then rising from a sitting to a standing position slowly, using assistive devices such as railings, canes, walkers, or furniture for balance and stability.

The home environment must not be overlooked in addressing the problem of falls and instability. Older homes of older people are often full of danger. These homes may have old and unstable furniture, beds and toilets that are too high or too low, uneven

stairs, and rickety or absent railings, throw rugs and frayed carpets, and poor lighting, which create hazards and danger for the older person.

INCONTINENCE

Incontinence is a stressful problem when it affects the older person. It is the inability to control one's bladder and/or bowels. The prevalence of urinary incontinence increases with age, is slightly higher in females, and is more common among older people in hospitals and nursing homes. People who have a problem with incontinence often live in the community, are ambulatory, and have good mental function. Incontinence does not mean incapacity.

Incontinence ranges in severity from occasional dribbling of small amounts of urine, to continuous loss of urine and feces. Many adverse effects result from urinary incontinence. They include:

Physical Health

Skin breakdowns (a very serious problem which leads to many other complications)

Recurrent urinary infections

Sepsis (serious and generalized infections)

Death

Psychological Health

• Withdrawal • Isolation • Depression • Dependency

Socioeconomic factors

Stress on family and friends

Predisposition to institutionalization

Costs of caring for incontinence

Supplies, laundry, and labor

Urinary incontinence is often not curable. **However, it can always be managed in a way that will keep people comfortable, make life easier for caregivers, and minimize costs.**

Management of incontinence is a challenge for the caregiver. Helpful approaches to managing incontinence include the following:

Supportive measures

Positive attitude

Use of toilet substitutes, i.e., bedside commodes and urinals

Avoidance of complications (do not let the treatment make the condition worse).

Avoid excessive sedation

Do not make toilets inaccessible

Avoid using drugs that adversely affect bladder function

Use protective undergarments when needed

Use absorbent bed pads

Bladder training and retraining (routines performed by patients and caregivers to enhance bladder control). Includes fluid restrictions, scheduled times for voiding, conditioning exercises (Kegels) to improve pelvic muscle tone.

Good skin care must be assured at all times.

Physicians may use the following to treat incontinence:

Drugs

Surgery to correct anatomical problems

Mechanical and electrical devices, such as artificial sphincters

Electrical stimulators

Catheters; types include external (condom or "Texas" catheter), intermittent, suprapubic, indwelling

MANAGING MEDICATION

Managing medication can be a complex and confusing problem for older people. They often take many different drugs on different schedules for different medical conditions. When older people see different doctors for different medical conditions, the problems of managing medications becomes even more complicated. Many older people do not take their medications at all because the drugs are too expensive or because it is too complicated to straighten out which medications to take at what time.

There are steps that can help to make medications safe and effective for the older person. The physician should prescribe as few drugs as possible.. This will reduce the problems of confusing schedules and will reduce medication expenses.

Caregivers should have instructions about what the medication is being prescribed for, when and how to take the medication, and what side effects to watch for. Instructions should also be given about when to call the doctor if the caregiver thinks there is a problem with the medication. A schedule for medications, printed in large letters, can be posted in a convenient location in the home. Other aids to help in taking the right medication at the right time include: bottles with tops that are easy to get off, and specially designed, clearly marked pill dispensers.

Older people should have their medications written down on paper. They can take that list with them when they see different doctors for different ailments. Caregivers can help the physician by keeping medication records updated and bringing them to each office

appointment. Over-the-counter drugs should be included in the list. If no list is available, the older person can bring all of the medications to the visit for the physician to see.

When older people have poor vision and hearing, it is important to make sure that they understand about their medications. The caregiver may need to assume responsibility for the medication when the patient is confused or otherwise dependent.

ACTIVITIES OF DAILY LIVING

The Index of Independence in Activities of Daily Living is based on an evaluation of the functional independence or dependence of patients in bathing, dressing, going to the toilet, transferring, continence, and feeding. Specific definitions of functional independence and dependence appear below the index.

A. Independent in feeding, continence, transferring, going to the toilet, dressing, and bathing.

B. Independent in all but one of these functions.

C. Independent in all but bathing and one additional function.

D. Independent in all but bathing, dressing, and one additional function.

E. Independent in all but bathing, dressing, going to the toilet, and one additional function.

F. Independent in all but bathing, dressing, going to the toilet, transferring, and one additional function.

G. Dependent in all six functions.

Other: Dependent in at least two functions, but not classified as C, D, E, or F.

Independence means without supervision, direction, or active personal assistance, except as specifically noted below. This is based on actual status and not on ability. Patients who refuse to perform a function are considered as not performing the function, even though they are deemed able.

Bathing (sponge, shower, or tub)

Independent: assistance only in bathing a single part (as back or disabled extremity) or bathes self completely.

Dependent: assistance in bathing more than one part of body: assistance in getting in or out of tub or does not bathe self.

Dressing

Independent: Gets clothes from closets and drawers; puts on clothes, outer garments, braces; manages fasteners; act of tying shoes is excluded.

Dependent: does not dress self or remains partly undressed.

Going to toilet

Independent: gets to toilet, gets on and off toilet, arranges clothes, cleans organs of excretion (may manage own bedpan used at night only and may or may not be using mechnical supports).

Dependent: uses bedpan or commode or receives assistance in getting to and using toilet.

Transfer

Independent: Moves in and out of bed independently and moves in and out of chair independently (may or may not be using mechanical supports).

Dependent: assistance in moving in or out of bed and/or chair; does not perform one or more transfers.

Continence

Independent: urination and defecation entirely self-controlled.

Dependent: partial or total control by enemas, catheters, or regulated use of urinals and/or bedpans.

Feeding

Independent: gets food from plate or its equivalent into mouth (precutting of meat and preparation of food, as buttering bread, are excluded from evaluation).

Dependent: assistance in act of feeding; does not eat at all or parenteral feeding.

Source: Katz, Ford, Moskowitz et al. 1963

Part V

Techniques For Coping With Caregiving

Giving Personal Care

Organizing Your Home Environment

Recognizing And Reducing Stress

Plans For The Future/Decision Making

Legal Powers

Part V: GIVING PERSONAL CARE

Observation

The informal caregiver, as the most important person in the home, is the eyes and ears of the formal care system. The caregiver observes signs and symptoms of illness and changes in functional ability. The caregiver asks questions about how the older person feels when changes in appearance or function are noted. Careful observation is important to determining how well the older person is doing. Observations are made all the time, while care is being given, during conversation, or whenever any interaction takes place.

Disease is not a normal process of aging. It causes the body to function abnormally. The caregiver can tell whether signs of illness are increasing or decreasing in severity. She can also notice social, emotional, and environmental conditions which may influence the person's reaction to illness and to treatment.

Each person responds differently to illness. Age has an affect on how a person responds to illness. **Symptoms are usually less clear in older people.** They may not have a fever in response to an infection or feel pain as acutely as a younger person. Therefore, it is often difficult to tell when something is wrong. Important things to look for are: **unusual quietness, depression, loss of appetite, confusion, or other behavioral changes.**

See Appendix - Guide to Personal Care

Home Safety Checklist

This check list is to help you make your home safer. Use it to go through your home and look at the items that are listed below. If you check "no" on any item, your home is not as safe as it could be. By correcting items marked "no", you can improve your home safety and help prevent home accidents.

1. Are there sturdy handrails or banisters by all stairs?
2. Is there adequate lighting in stairways and hallways?
3. Is there a light switch at both the top and bottom of stairs?
4. Are stairways and hallways clear of clutter and loose objects?
5. Is there a light switch by the doorway of each room?
6. Is there a flashlight, lightswitch, or lamp beside your bed?
7. Are all electrical cords placed close to walls, out of the way?
8. Are rugs secured around edges?
9. Are rugs smooth and flat, with no folds or wrinkles?
10. Is there a list of emergency phone numbers by your phone? Fire, Police, Emergency, Ambulance?
11. Are all medicines marked clearly? Name of medicine, date purchased, how taken, when taken?
12. Is there a non-skid surface on the floor of the bathtub or shower?
13. Are there adequate hand holds for getting in and out of the bathtub?

Other consideration for the home:

1. Space can be organized for orientation, information, and safety.
2. Environmental messages can be organized through the use of redundant cuing, landmarks, and color coding (same messages through a number of channels).
3. The use of color and/or textural differences to clarify boundaries. Use of texture and pattern in drapes, wall hangings, and rugs adds warmth and comfort, and heightens the sensory awareness.
4. Visual adaptations: More intense illumination for specific activities without increased glare.
5. Varying sources of light are needed. Glare is a serious problem. It constricts the pupil and allows less light to enter. Highly polished floors in long halls, lit by overhead lights can cause glare and visual distortions. Side lighting, rugs, and low reflective polish can cut down on glare. Sunlight streaming into a room can be minimized by the use of drapes and by painting walls in non-reflecting paint and glare absorbing colors.
6. The eye is less able to accommodate and focus for clear vision at varying distances. The implication is: more time is needed to focus.

RECOGNIZING AND REDUCING STRESS

Everyone experiences stress in a variety of different situations. Caring for an older person can be particularly stressful. Your body responds to stress in a number of ways. For example:

Nervous system activity increases

Blood pressure goes up

Muscles become more tense

Need for oxygen increases, and breathing rate goes up.

A "relaxation response" has the opposite effect. By engaging in the relaxation response, the nervous system slows down. Blood pressure decreases as does muscle tension and rate of breathing.

You can learn to call forth a relaxation response through stress management exercises like deep breathing and progressive relaxation.

With practice of stress management techniques, you can increase your ability to regulate the undesirable response you experience. You can enjoy increased wellness by incorporating stress management techniques into your developing "healthstyle." Following are some techniques for relaxation.

Lie comfortably on your back in a quiet place. Allow yourself to become passive.

Begin by taking a few deep breaths and then relaxing into your natural breathing rhythm.

Tense and release groups of muscles one at a time. Begin with your feet, tense muscles, hold for a count of five and then release. Move up to your lower legs. Tense, hold, and release. Continue to move up to your body--upper legs, buttocks, abdomen, chest, shoulders, arms, hands, and face.

Notice what the tension feels like as you contract muscle groups. Focus on the experience of letting go of this tension as you progressively relax parts of your body. Allow the tension to float out of your muscles as you let them go as limp as you can.

Practice this relaxation technique once or twice a day for 5-10 minutes. It is a wonderful inducement to sleep and can be easily taught to your carereceiver either in a sitting or lying down position.

Walking is one of the best and safest all-round exercises for older adults. Brisk walking is an aerobic activity that strengthens the heart and lungs and improves endurance. No social skill is involved, there is no charge, it can be done almost anywhere, in solitude or with companions, and it has a lower injury rate than most other exercises.

A good walking workout depends upon stepping up your pace, increasing your distance, walking more often. Here are some tips to help you get the most out of walking:

1. Walk steadily and briskly.
2. Breathe deeply through your nose or mouth, whichever is more comfortable.

3. Wear comfortable clothes that allow you to take long, easy strides. In cold weather wear several layers of light clothing so you can remove the layers as you warm up. A scarf and cap are crucial in very cold weather.
4. Lean forward slightly when walking up hills, and be sure to breathe deeply.
5. Land on your heel and roll forward to step off the ball of your foot. Soreness may result from walking flatfooted.
6. Keep your head erect, shoulders back and relaxed, and your back straight. Your toes should point straight ahead and your arms should swing freely.

Note: Both caregivers and carereceivers (if able) will benefit from this activity. It is particularly beneficial for carereceivers who experience mental stress.

Here is an instant relaxation procedure:

Position yourself comfortably either sitting, standing, or lying down. Keep your back straight.

Draw in a deep breath and count to five slowly. Exhale slowly and tell all your muscles to relax. Repeat this step two or three times until you are completely relaxed.

Imagine a pleasant thought, such as a calm lake. You can use a natural scene as vividly as you can.

Practice this instant relaxation skill during your daily routine when you feel unwanted tension - for example, when you feel yourself becoming impatient while waiting in line.

Note: All of these anti-stress activities (handouts 6-8) can be done by informal caregivers with their elderly carereceivers, if approached with caution and patience.

AFFIRMATIONS TO ENHANCE WELL-BEING

People who are caring for others for extended periods of time will experience many different types of stress. The following are techniques to relieve the stress and enhance well-being.

Affirmations are self-statements for positive attitudes. Attitudes influence how we think, feel, and act. If you choose, you can practice the mental sets that are meaningful to you to help you increase positive and relaxed approach to caregiving. You can gradually weave these into your life fabric.

Please do not make these affirmations new "shoulds" for yourself. Results will become evident as you introduce these attitudes into your daily life.

- I do the best I can about a situation, committing myself to its resolution without worrying.
- I set realistic goals for myself. When reasonable, I do one thing at a time.
- I am aware of my own feelings and can choose to express them honestly to other people: I am responsible "to" others, not "for" them.
- I have no need to compare myself with other people.
- I treat my elderly carereceiver with the respect and acceptance I will for myself.

• I realize there are options in any given situation and positive experiences.

• I learn lessons of growth from both negative and positive experiences.

• I think and live positively, committing myself to achieving personal excellence; if I backslide, I can regroup and go on.

• Death is a normal, inevitable part of human life.

• I live in the present moment, realizing I can learn from the past and have hope for the future.

• By keeping in touch with my body and responding to its needs, I choose to be well and happy.

It usually takes from one to four weeks of daily practice to gain some benefits from the mental sets. Regular and consistent practice is important. Don't worry about the results, they will come with time.

1. Choose the mental sets which you believe will help you the most. Focus on those until you experience the results you want.
2. Revise the mental sets so they are relevant to your particular situation. For example, #3 can be changed to "I am aware of my own feelings, and express them honestly to my husband (neighbor, daughter), etc.
3. Pick a time of day for practice when you are relaxed and your mind is clear. For some people, early morning is best, for others, late evening or while walking in a park may be better.

4. If negative thoughts surface in your mind as you practice, let them pass without dwelling on them. It does take some time to change beliefs and attitudes, and in the meantime, old negative thoughts may appear. If they persist, you can **"stop"** then focus on the mental sets.
5. Repeat **daily**, either silently or out loud, or write them down ten times daily. Spend five to ten minutes each day with them. Say or write them in a relaxed way, as if they are true for you (even if you are not quite convinced).
6. Imagine yourself living by the mental sets you have chosen.
7. Write the mental sets on 3 x 5" cards and place them somewhere (the refrigerator door, bathroom mirror, beside a table) where you will see and read them daily. Rewrite or move these cards to a new location every three or four days to reinforce noticing them.

PLANS FOR THE FUTURE - DECISION MAKING

Decision making is closely related to being independent, being responsible, and having control over one's life. Decision making is an important process of personality growth and adulthood. When decisions must be made about the future of the older adult's living arrangements, involve the older person whenever possible. This is particularly difficult when the decision involves bringing extra help into the home or nursing home placement. Common feelings that arise at these times include guilt, anger, frustration, and hostility. Respecting the values and feeling of the older adult, the caregiver, and the entire family helps to encourage open, honest discussion by all participants.

Making wise decisions includes gathering information and facts and looking at all of the alternatives. This includes an assessment of the situation today and an honest, realistic plan for the future. It may seem difficult or impossible to include the older adult in the decision making process. Each older person is unique and ages in an individualistic way. Sometimes things go smoothly, sometimes they don't. Occasionally difficult behaviors such as exaggerated complaints, refusal to accept a situation, manipulation, and confusion make a joint decision nearly impossible. Try to be understanding and reassuring during stressful times. Try not to be judgmental and argumentative. Be realistic and faithful to your own needs and obligations. If the older adult is physically or mentally unable to make the decision, you may have to assume the lead role.

Include evaluations from the doctor, nurse, and other health care and supportive staff to assist you in the decision making process.

Resources

The following list of resources will help you identify providers in your community offering a number of services to help you in your caregiving role. Please add additional services which you may need and which are available in your local community. Remember, these agencies are here to help you, but you need to let them know that their help is needed.

Community Resources

Rhode Island Department of Elderly Affairs
79 Washington Street
Providence, RI 02903 **277-2858, 277-6880**

The Department provides a large number or services through many programs offered in the community. **Information and Referral** is a telephone service that will get you in touch with the right resource or service. Call 277-2880. There are many pamphlets and directories available which list telephone numbers and contact people. **The Pocket Manual** lists all of the services available through the Rhode Island Department of Elderly Affairs.

Widow/Orphan Handbooks listing resources throughout the state-

A Directory of Human Service Agencies in Rhode Island 1986
The United Way of Southeastern New England, Inc.
229 Waterman Street
Providence, RI 02906

A comprehensive listing of various community services agencies which was assembled to "increase the organized capacity of people to care for one another."

Rhode Island Department of Health Handbook
79 Davis Street
Providence, RI 02103

Support groups centered around various topics are important resources in every community. The Department of Elderly Affairs is currently compiling a listing of support groups throughout the state.

Legal Powers: Planning for Incapacity

Adult children of elderly parents and caregivers of whatever relationship need to know more than the whereabouts of important personal papers and financial information. They must be familiar with a variety of legal documents that may be needed should the person for whom they have responsibility becomes incapacitated.

A power of attorney. There should be a general, durable power of attorney between husband and wife so that if one becomes incpacitated, the other has access to all the couple's assets and is empowered to act in the other's behalf. For someone whose parent is alone, a durable power of attorney can be useful in case the parent is eventually unable to handle his or her own affairs. A durable power of attorney does not terminate if the principal party becomes incapacitated physically or mentally. A nondurable power of attorney is revocable. Rhode Island Public Law, Chapter 86-190, states the statutory durable power of attorney for health care.

A power of attorney can be general or restricted to certain aspects such as banking, filing tax returns, or collecting government benefits. The limited power of attorney may be more palatable for a parent who is resistant to the idea, yet may be ineffective when quick action on a variety of matters is needed. The better alternative is to write a durable power of attorney that would not be used until needed in defined situations, such as disability or incompetence.

A living trust. According to the Reasearch Institute of America, Steven Perlis, 'a lawyer with the United Charities of

Chicago, advises that children should try to get power of attorney for a parent over age 70 and should have that parent establish a living trust. Both vehicles can assure that the parent's affairs would continue to be managed smoothly, should the need arise. In a living trust, the person names himself or herself as the trustee; when that person is certified by a physician as being incapacitated, the successor trustee then becomes the primary trustee. This may be valuable if the parent's assets are substantial and/or widely diversified. Smaller assets may not justify the cost of setting up and maintaining the trust. When the parent can longer manage financial matters, the person named as successor trustee steps in to administer the trust.

A living will. "In general discussion with parents, the subject of a living will should also be addressed. In essence this statement, made by a parent of sound mind, that if he or she were ever certified by the attending physician and one other as being terminally ill, no life-sustaining devices would be used to artificially prolong life. This document circumvents the expense, indignity, and frustration that surviving family members experience all too often with artificially prolonging vital functions.

If a decision is made to draw up a living will, the parent must notify all doctors who treat him or her and see that the document becomes a part of his or her medical records whenever entering a hospital for treatment. Attorney Perlis advises discussing and executing such a document with an attorney to understand its full effects and to ensure that it is handled as legally as any other will. The document is revocable, and if a decision to revoke is ever made,

the original and all copies must be destroyed" (from Caring for Dependent Parents, Reasearch Institution of America, Inc.).

At this time the no living will law is in effect in Rhode Island. The above procedure should be followed, however, to clearly spell out for family and physicians the wishes of the individual.

Appendix I

Personal Care Guide

Resources For Visual Impairment

APPENDIX

Hygiene, Grooming, and the Environment

This section addresses mainly the older person confined to bed for any number of reasons. Frail, older persons who are up and about may need assistance with hygiene and grooming. The type and amount of assistance will be different from that needed by someone in bed, but the principles that follow remain the same. In all instances, it is important to have the person receiving care do as much as possible by and for himself or herself. Thus, the caregiver may need only to provide the things necessary for bathing and grooming for one individual, where another may need the entire task done. Be flexible, individualize the care for each person according to need.

A person may be confined to bed for a variety of reasons. Surgery, convalescing after a stroke, a long-term illness such as cancer, a short-term illness such as the "flu" (influenza), or a frail stage of health are just a partial listing of circumstances that confine a person for a period of time. The total needs of the person confined to bed must be considered. You may remember those needs from a previous chapter. They include love and affection, recognition, acceptance, security, trust, socialization, food, clothing, shelter, rest, activity, and avoidance of pain and danger.

People have many different feelings about being confined to bed. Common feelings include embarrassment or reluctance about needing personal services, anger, feelings of dependency, helplessness, a decreased self-image, not wanting to be touched,

amd many others. It helps to talk about such common feelings and to treat the frail, older person with the kind of understanding care that we would all like to receive if we were in that position.

Attention to the environment can improve the safety and comfort of the older person confined to bed. Essential items in the environment include good lighting, a way to call for help, kleenex, books, magazines, or other personal items kept in easy reach. Keep the person comfortably warm with adequate bedcovers and room heating. Electrical cords should be kept out of the way so those working around the bed will not be tripped nor the person in the bed become entangled. Frayed cords and loose connections create fire hazards and, of course, should be avoided. Rooms should be well-ventilated and free of drafts.

A fire escape route should be determined and understood by the person in bed and by all family members. Smoke detectors should be installed. Labels on the doors and windows of rooms where there is a handicapped or bedridden person is an additional safety step.

Fire departments in many communities supply stickers and/or other types of identifying labels.

Body Mechanics

Caregivers must stay healthy and free of injuries. Knowing and using good body mechanics when caring for another person will help to avoid back injuries and other muscle strains and pulls.

Good posture helps to maintain a comfortable and workable position. Good posture means holding head erect, stomach muscles tight, buttocks pulled in, back straight and shoulders comfortably back. An exaggerated or stiff position is not necessary. Use a wide base of support, with feet apart and one foot forward when standing for a long period of time. This position maintains balance and a comfortably low center of gravity. Keep the back straight and the hips and knees slightly flexed (bent).

Never bend from the waist to pick up or move a person or an object. Use the large muscles of the legs for lifting. Do this by flexing the knees and hips and pushing up with the upper leg muscles when lifting. Point the feet in the direction of the movement for side and forward motion, in most instances. This prevents twisting of the spine and allows movement with the body in good alignment. Stay close to the person to conserve energy and prevent strain. Work at waist level whenever possible (a hospital bed is helpful).

The position of the person who is lying in bed is very important. Correct body position (or alignment) means:

- Position the person up in the bed. When the head of a bed is elevated, the person tends to slide down and may be slouched

over. This causes pain and discomfort as well as creating pressure on certain bony body parts.

- Give support to the curves of the spine with a pillow under the head and neck; the pillow should reach down to the shoulders.
- Support body joints using pillows, towels, or folded washcloths.
- Support legs to relieve pressure on hip joints with a small pillow or pad placed under the ankles. Padding between the ankles and knees helps prevent pressure in these areas.
- Change the position of the person in bed frequently. When the person cannot move himself, help him/her to turn from side to side. This helps to improve circulation, improve muscle tone, and to prevent contractions and joint deformities. It also helps to prevent pressure sores on ears, heels, buttocks, elbows, hips, and other bony body parts.

(The technique of moving the person in bed from side to side, into a semi-sitting position, of getting a person from a bed to a chair and back to bed should be demonstrated in a class situation or individually with the caregiver at the bedside).

When providing care to another person, talk about what you are doing as you move along. This prepares the person for what is going to happen and relieves a certain amount of fear and anxiety about the procedures that are to follow. Talking while caring is a good way to open communication and help the older person talk about his/her feelings.

Bathing

A bed bath is given for the following reasons:

- to cleanse and refresh the person
- to aid in the elimination of wastes from the skin
- to aid in stimulating circulation
- to provide passive and active exercise

How often a bath is given depends on such factors as the physical condition of the person and the condition of the skin. Older people have less oil in their skin and may be more sensitive to soaps. They also perspire less. Although frequency of bathing is an individual decision, it is important to keep the rectal and genital areas and underarms clean and dry. Bathing, followed by a back rub, rubbing pressure points with lubricating cream, providing clean clothing and bedclothing, and repositioning the person in bed are very important and comforting procedures provided to the person in bed.

A few points to follow in bathing a person:

- Choose a time convenient for both parties
- Make sure the room is warm
- Organize the equipment
- Keep the person warm with a sheet or blanket while bathing, uncovering only one part of the body at a time
- Place a towel under the part of the body being washed to keep the bed dry
- Change the bath water when soiled, soapy, or cool

- Test water to be sure it is not too hot or too cool
- Provide as much privacy as possible
- **Use bathing time to assess the condition of the person as he/she is bathed - note changes in the skin, especially look for reddened skin, blisters, broken skin, darkened skin areas**
- Use soap sparingly, use glycerine or other non-drying soap
- **Encourage the person to bathe himself as much as possible.** Bathing oneself helps the person in bed to get some exercise and to maintain more self-sufficiency.

Directions For Giving a Bath

Explain what will be done and the reasons.

Place a cover over the top cover to be used as a bath blanket. A bath blanket may be made by sewing several large towels together. Slide the top covers from under the bath blanket. Help remove the person's bedclothes.

Place a towel under the person's head.

Wrap the washcloth around the fingers and palm, anchoring it with the thumb; fold over the part extending beyond the fingers and tuck under at the bottom edge of the cloth (this eliminates dangling ends which may annoy or irritate the person being bathed).

Wash eyes first - with clear water, cleansing from the inner corner to the outer corner of the eye, using opposite corners of the cloth for each eye.

Wash face from the midline outward, using a firm but gentle motion. Use clear water unless a particular soap or cream is preferred. Dry all areas immediately after they are washed.

Wash and rinse ears. Dry them.

Place a towel under the arm and another towel near the hand and the basin.

Lower the person's hand into the basin; allow it to soak as the arm is being washed.

Wash and rinse the other arm and soak hand, drying carefully, especially between the fingers. Push cuticle back and clean under nails.

Put towel over the chest and abdomen; bring bath cover down to thighs.

Wash, rinse, and dry neck, chest, and abdomen. Cover chest and abdomen. Pay careful attention to the skin around the ostomy (for the person who has an ostomy).

Remove bath cover to expose the leg and place towel under the leg.

Place a towel under the basin placed near the foot.

Lower foot into the basin.

Wash, rinse, and dry leg.

Repeat above steps with other leg.

Dry carefully between the toes.

Observe feet and use pumice stone or emery board to smooth callouses. Clean under nails.

Turn person on his or her side, drape sheet around back and buttocks.

Wash, rinse, and dry back and buttocks; cover his back.

Place a towel under his/her buttocks. Wash carefully between buttocks. For women, be sure to wash the genital area carefully front to back to avoid bringing bacteria from the rectal area to the vaginal or urethral area. If a person is able, have him or her wash the genital areas in the same way as described above.

If the person has a catheter in place, wash carefully around it with soap and water, and dry the area well. If able, teach the person to wash in the same way.

Apply body lotion and/or powder lightly as desired. Wipe away excess powder with a dry towel. When used **lightly**, powder can be

helpful in wicking away moisture. But be careful to avoid leaving excess powder in crevices where it will retain moisture and irritate or macerate the skin.

Keep nails short and smooth. For diabetics and those with circulatory problems, nail care by a podiatrist is recommended.

Mouth Care

Mouth care is given to provide the person with a feeling of cleanliness and well being, to prevent gum disease and cavities and to keep the mouth moist and free of odor.

Equipment needed:

- soft-bristled toothbrush
- towel
- toothpaste (bicarbonate of soda, salt, or dentrifice)
- dental floss
- glass of cool water
- emesis basin or empty container
- drinking straw
- swab
- moisturizer for lips and mouth

Organize the equipment and bring it to the bedside. Place equipment withing easy reach of the person so he can do as much of his own dental care as possible.

If the person needs help with brushing:

- explain what will be done
- put the person in an upright position if possible; if not, turn the person onto his side so the saliva and fluids can run out by gravity
- place a towel under his head
- place emesis basin under chin of the person sitting up, and also at the side of the face for the person lying down in bed

- gently brush the teeth and tongue
- place toothbrush at an angle against the gumline and gently scrub back and forth with short strokes; use this same procedure on all chewing surfaces, tilting the brush to get at the inside surface as well.

Flossing:

Flossing is an important procedure which helps to maintain healthy gums in the person who still has his or her own teeth. It provides stimulation to the gums, prevents bacteria from growing in the gums around the teeth, and prevents formation of placque which in turn leads to gum disease.

Procedure for flossing:

- Break off approximately 18 inches of dental floss and wrap most of the dental floss around the middle finger of one hand and the rest around the middle finger of the other hand, with about one inch of floss between the hands.
- Use the thumb and forefinger to guide the floss (a floss holder may help to reach back teeth).
- Gently insert the floss between the teeth using a sawing motion.
- Curve the floss in a letter "C" around the tooth at the gum line.
- Slide it gently into the space between the tooth and gum; hold the floss, curve it around the tooth next to it and scrape it with the floss.
- Repeat this process for each tooth.

To Care For Dentures

The person who has dentures may need help in caring for them. He should be encouraged to wear them most of the time, but they should be removed and cleaned at least once a day.

Procedure:

- Wash hands before and after handling dentures.
- If the person cannot take them out himself, use a tissue to lift one end of the denture to break the suction and to pick up the dentures.
- Place dentures in a container filled with water.
- Clean over a basin filled with water to avoid breakage if the dentures are accidentally dropped.
- Use a denture brush or soft toothbrush and cleaning agents such as peroxide or baking soda and water, or the person's preference of a cleaning agent.
- Store dentures in liquid when not in the person's mouth to avoid denture warp.
- Apply denture cream or adhesive as needed
- Bring mouthwash and basin to the bedside so the person can rinse his mouth before the dentures are reinserted. Check gums and tongue for sore spots and food deposits. Remove food deposits with soft cloth if necessary.

Foot Care

Foot care is an important part of personal care. Good foot care helps to make a person feel good all over, in addition to promoting

overall health. Special foot care is required by people who have certain conditions which affect circulation. Diabetes is the best known example of this. Observe the feet for any unusual appearance; note reddened or darkened areas, sore, irritated areas, swelling, and discoloration of the nails. Note if there is a difference in temperature between one foot and the other.

Procedure:

- Soak the feet first
- Dry carefully, especially between the toes
- Clean nails, being careful not to break or puncture the skin
- Use pumice stone or emery board to smooth callouses and nails.
- If not contra-indicated, massage the feet, heels and legs with lotion, which helps to improve circulation and to relax.
- Trimming of toenails should be done by a professional because of the danger and seriousness of infections of the feet in those with circulatory problems.

Giving a Back Rub

Back rubs help to increase circulation, prevent bedsores at pressure points, relax the person, and increase comfort.

Procedure

- Explain what will be done
- When you are giving a backrub, stand comfortably at the side of the bed with your knees slightly flexed (bent) so that you can rock gently as you apply pressure to your patient's back
- Place person on his abdomen or on side

- Put lotion or cream in own hands and warm before applying to the patient's back
- Beginning at the lower back and moving upward toward the shoulder, apply pressure with the palms of both hands, and sweep upward, outward and down, using long, gentle strokes
- Note any bony areas and massage them gently
- Do not leave skin sticky with cream. Dry skin with towel and apply powder lightly if desired.

Preventing Pressure Sores

Pressure sores are to be avoided whenever possible. It is much better to prevent them than to treat them. The following measures will help to avoid them.

- Help the person in bed to exercise to the extent possible. Exercise helps improve circulation which helps to keep the skin in good condition.
- Turn the person who cannot move by himself frequently to avoid pressure on one area for a prolonged period of time.
- Pull the bottom sheet as taut as possible and keep the sheet free of irritants such as wrinkles, crumbs, etc.
- Keep the person's skin clean and dry.
- Massage pressure areas frequently to stimulate circulation. Include all bony areas such as the tailbone, hips, shoulders, heels, and elbows.
- Washable sheepskin or chamois skin may be placed under the person to relieve pressure and protect the skin. Foam rubber cushions or pads under bony prominences also helps to relieve pressure.
- Encourage good nutrition to help nourish and heal body tissue
- Report any areas of redness to the primary care provider or to the Visiting Nurse.

Handling Body Wastes

In giving personal care, it is important to learn how to dispose of body wastes. Body wastes from the sick room may carry

infection and must be disposed of carefully to reduce the spread of infection. Wastes may include used paper tissues, sputum, dirty dressings, uneaten food, body excreta, and vomitus. Avoid handling wastes directly with the hands whenever possible. Solid wastes may be picked up with tongs, a spring clothespin, or covered with a paper towel. The soiled material should be placed in a paper or plastic bag and disposed of. Turning the top of a paper or plastic bag down to make a cuff will help to keep it open, protect the hands when closing by providing a clean area under the cuff. You can close the bag by slipping your fingers under the cuff and turning the dirty side in. Grocery bags, newspapers, or whatever material is available may be improvised as a container for soiled materials and solid wastes. Plastic gloves may also be used as added protection in handling contaminated materials.

Liquid wastes should be disposed of by pouring them into a container that has a lid (this is done in the person's room) and then pouring the contents into the toilet. The container holding the liquid should then be washed with soap and water. Raise the toilet seat when pouring liquid into the toilet bowl to avoid splashing the seat.

Hands are the principal source of carrying germs and transmitting infections and other diseases. When providing personal care, **handwashing is important to everyone. Always wash hands with soap and water before and after providing personal care and immediately after handling contaminated materials and wastes.**

RESOURCES FOR BLIND AND SENSORY IMPAIRMENT

For Pamphlets on Preventive Care

National Council for the Prevention of Blindness
79 Madison Avenue
New York, NY 10016

Products (Aids and Appliances) for the Visually Handicapped

American Foundation for the Blind
15 West 16th Street
New York, NY 10011

Large-Print Reading Materials at Low or No Cost

National Association for the Visually Handicapped
305 East 24th Street
New York, NY 10010

For Printed Materials, Talking Books, and Braille Reading Material

American Printing House for the Blind
1839 Frankfurt Avenue
Louisville, KY 40206

Discounts on Books (No Minimum Purchase), Large-Print Book Reviews

The Large Print Book Club
G. K. Hall & Company
70 Lincoln Street
Boston, MA 02111

Free Reference Circular Telling Where Materials Can Be Obtained

Library of Congress
The Division for the Blind
Washington, DC 20542

Especially for Braille Materials

Howe Press of the Perkins School for the Blind
Watertown, MA 02171

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Appendix II

I. Myths And Realities of Aging

II. Characteristics Of Older People Who Receive Care

III. Assessing The Caregiving Situation

IV. Guidelines For Encouraging Communication

V. How To Communicate With Confused Older Adults

VI. Allowing For Reminiscence

VII. Working With The Older Person

HANDOUT I

Myths and Realities of Aging

Discuss the following myths about aging and compare them.

MYTH: Most older persons are alike.

REALITY: In fact, in their attitudes, abilities, personalities and interests, older people are equally as different as people of any age group.

MYTH: Older people are sick and disabled.

REALITY: In fact, most older persons are well and functioning independently in their communities. While three out of four older people have at least one chronic health condition, most are not significantly limited in their ability to perform activities.

MYTH: All people become senile when they grow old.

REALITY: In fact, dementia, or partial impairment, is not a normal process of aging. Less than 10% of the older population suffers from dementia and some forms of dementia are reversible.

MYTH: A sizable percentage of older people live in institutions.

REALITY: In fact, the majority of older people live in their own homes in the community. Only 5% of those over 65 are living in nursing homes.

MYTH: Older people are beyond the age when they can contribute to society.

REALITY: In fact, older people have many valuable assets, such as time, energy, experience, and skills.

MYTH: "You can't teach an old dog new tricks."

REALITY: In fact, many older persons are involved in new learning experiences. While the amount of time required to learn new information or skills might increase slightly with age, ability to learn does not diminish.

MYTH: Older people no longer have sexual desires.

REALITY: In fact, sexual needs and desires do not change significantly with advancing age.

MYTH: Old age is a time of tranquility.

REALITY: In fact, older people often face numerous stresses, such as debilitating conditions, decreased mobility, decreased income, increased medical expenses, and loss of loved ones.

MYTH: Most older people are preoccupied with and fearful of death.

REALITY: In fact, the majority are not afraid or preoccupied with death. Most desire to be told of impending death and most prefer to die at home.

HANDOUT II

Characteristics of Older People Who Receive Care

Here are some important characteristics of older people who receive care. These are not in order of importance. They are presented here to help us better understand the people who need our care. It is important to keep in mind that older people, like younger ones, are as different as they are alike, and therefore we cannot make broad generalizations.

Do these points hold true in your caregiving situation? Discuss each one. From your experience, what are some other characteristics of older people who need care?

1. Nearly ninety percent of people currently receiving care have some hearing loss. This can make them feel isolated and sometimes confused. They might not hear soft comments and could misunderstand the meaning of what you say.

2. Their eyesight is often not clear. Things at a distance can be misinterpreted or mistaken. Colors might not retain their true intensity. Often color schemes seem bizarre.

3. They have a need for touching and reassurance. Physical contact is very important.

4. Most of their lives they have taken care of others. Now it is difficult to accept that others must do things for them.

5. A spirit of independence is strong in most older persons. They want to do things for themselves and maintain their independence as long as possible. This is often difficult for caregivers who must balance concern for safety with allowing independence that could lead to accidents or falls.

6. A support system is vital to their well-being. Some older people rarely ask for help, yet are pleased when assistance is offered. It becomes the responsibility for the caregivers to take the initiative in finding out how things are. Other older people might be demanding of caregiver's time and insist on constant attention.

7. Some frail, older people seem to withdraw and live in the past. At times the pace of the present is too difficult to understand and maintain, so they retreat to the familiar.

8. Personal care must always respect the dignity of the person. Attitudes about personal care and self-respect will vary among older people. Members of the older generation were reared in a much stricter and modest environment than today's younger adults.

9. Long-term memory is often better than short-term memory. Older people will often refer to circumstances that existed during their childhood. Stories from the past can abound. They need to be listened to, though they might repeat themselves.

10. Short-term memory may decline. Often frail, older people lose things because they can't remember where they put them. To provide mental stimulation, such activities as reading, discussing current

events, working croosword puzzles, even arguing with others can be important to enhance short-term memory.

11. Allow the frail, elderly individual the dignity of being a respectable human person who has rights and responsibilities. He/she has the right to be treated as a person and not an object. This dignity must be maintained to the end and evidenced in allowing the person to die with the same dignity intact.

HANDOUT III

Assessing the Caregiving Situation

The Following are guides for setting up a cooperative situation within the family in providing caregiving services.

Patience will be needed by everyone. It is difficult to give care to an older person but it is just as difficult to receive care from a younger person. An awareness of what it is like for each will help all family members make necessary adjustments.

1. Identify your caregiving situation. Look at the positive and negative aspects of the situation.

2. What are your own feelings? Feelings of guilt, helplessness, frustration, or fear of loss are all commonly felt and are normal reactions to the situation you are now facing.

3. What is the emotional state of the person receiving care? He/she may be lonely, sad, angry at being dependent, anxious, or afraid.

4. Describe the person receiving care as he or she is now, ten years ago, and as a young person. This helps to see the individual in a more complete picture and as a whole person.

5. What are the strengths and limitations of the person receiving care?

6. According to the person receiving care, what does he/she see as the strengths and limitations of themselves?

7. What activities for the person receiving care are acceptable and agreed to by both parties?

8. What activities are **not acceptable**? Discuss these and agree upon compromises when necessary.

9. What are the ongoing needs of the person receiving care? For example: to be taken to church, to have medicine picked up, etc. Discuss and agree upon these items. This is one way to relieve the older person of feeling that he or she is always in a position of asking to have many things done.

10. What is the person receiving care responsible for or for reminding someone else to do? Discuss and agree upon these items.

Remember:

Always encourage the older person first to make the decision or share the decision making-process. Only make a decision for another person if that person is completely unable to make a decision. It may be that the person receiving care must be prepared to make the next move: to accept a home health care aide, or enter a nursing home. Involve the individual in the decision-making process to the maximum extent whenever possible.

Remain flexible and open to change. The first decision may not be the best and circumstances may change. New problems and factors may arise at any time.

Reevaluate and reassess the situation as well as your own needs and feelings frequently. Be ready to seek and accept outside help when needed.

HANDOUT V

Guidelines for Encouraging Communication

- Really listen
- Pay attention
- Repeat using different words
- Speak distinctly
- Talk directly to them
- Take your time, one thought at a time
- Acknowledge feelings
- Don't suppress feelings
- Use non-verbal clues
- Be aware of your tone of voice
- Touch
- Listen to silence
- Try to read between the lines of what is being said
- Encourage and reassure
- Maintain eye contact and don't talk down

These points are important enough to elaborate on them as follows:

1. **Really listen** to what they are saying. Respond to them. This assures the person that you are indeed listening.

2. **Pay attention** to what they are saying and to what you hear. You should ask them to repeat something if you are not sure, saying: "I didn't quite understand what you meant" or "I didn't exactly hear you correctly, could you repeat it for me?" (Or, you may want to repeat back to them what they have said and ask if that is what they meant).

3. **Repeat** what you said using different words which convey the same meaning.

4. **Speak distinctly**, keep objects such as books, magazines, your hands, etc. away from your mouth.

5. **Talk directly to them**, face to face. Sit as close as is comfortable for both of you. Don't shout, talk over your shoulder, or shout at them from another room.

6. **Take your time, present one thought at a time**. Do not jumble or switch back and forth from one thing to another. Remember, the older person may have a slower reaction time. It may take him/her a little longer to respond, to assimilate what you are saying.

7. **Acknowledge feelings**. If the person indicated he or she is feeling sad or happy make some indication that you understand that feeling and/or empathize with it; i.e., "I think I know how you feel, Mom" or "You feel pretty good about that, don't you?"

8. **Don't suppress** your own feelings; use "I" statements; i.e., "I feel very good," or "I feel bad" or "I don't care for that very much."

9. **Pay close attention to non-verbal clues** such as facial expressions, hand gestures, or the way they are sitting. You can tell how people feel about a particular situation if they are sitting back and look relaxed as opposed to being on the edge of their seats. Watch for eye contact as well.

10. **Pay attention to the tone of voice** they use. If it is low and hushed or bold and loud. The tone conveys different messages or meanings. Your tone should be pleasant.

11. **Touch**, a simple touch on the shoulder, is often reassuring or comforting.

12. **If they are silent** for long periods of time or refuse to talk about particular topics or events, this too can be a means of letting you know how they feel.

13. **Look for hidden meanings**. Maybe they are trying to tell you something indirectly! Use your intuition and to try and select out what they may be trying to get at in a round-about way.

14. **Try to encourage them**, assure them that you want to talk, listen, or are concerned.

15. **Never talk down**. Remember, they are adults. Be attentive and honest with them and with yourself. Look directly at the person when conversing.

HANDOUT VI

How To Communicate With Confused Older Adults

Discuss the following statements in the light of your caregiving situation.

1. Make sure you have their attention - use eye contact and touch.
2. Identify yourself (and relationship if necessary). Use the older person's name frequently.
3. Be clear about expectations. Be specific and short; make known what you expect; be concrete, show and tell.
4. Give the feeling that you assume they can and will do what you expect. Choices within the process are important, request - do not order, do not pull or push.
5. Do not lie - trust is crucial with the confused. Talk about reality; talk about what you will do.
6. One person takes primary charge and responsibility. Others may assist. Use one approach at a time.
7. Keep to a routine - keep calm - keep slow.

HANDOUT VII

Allowing For Meaningful Conversation: The Reminiscence

Definition of Reminiscence: **"A way of reliving, re-experiencing, or savoring events of the past that are personally significant." Reminiscence gives the older person a means to:**

1. Maintain self-esteem and reinforce a sense of identity.
2. Feel a sense of achievement and pleasure.
3. Cope with stresses relating to the aging process.
4. Gain status by revealing selected elements of his/her life history.
5. Place both positive and negative aspects of the past in perspective.
6. Deal with emotions such as grief.
7. Establish a common ground for communication.

It helps the open and interested recipient to:

1. Gain knowledge and understanding about the older person and the period in which he or she has lived.
2. Build a bridge between past experience and the present.
3. Establish a mutually satisfying relationship through the sharing of information and experiences.
4. Use a person's history as a therapeutic tool in building programming or establishing resources for others.
5. Have a context for gaining clues about the person's behavior in the present.

HANDOUT VIII

Working With the Older Person

The goal of caring for an older person with a cognitive impairment is to improve the individual's ability to function. The underlying cause must be identified and corrected. This may mean treating a disease or changing the medication. After that, supportive measures and other management techniques are useful in improving the person's overall function and well-being. Such supportive measures are varied and must be uniquely suited to the individual situation.

Read through the following and record key information relevant to the person for whom you are caring.

1. Assess the environment. Sometimes it is important to make no changes in the environment since changes add to confusion. At other times alterations can be made to simplify the environment. What should be changed in your working environment?

2. Encourage physical and mental activities. Moderation and good judgement are needed. It may help to avoid situations that stress intellectual capabilities. Decision making can sometimes be nearly impossible for some older people. Simple decisions are as difficult as complicated ones. You can assist the older persons in making

decisions by limiting the number and complexity of decisions to be made. For example, you make the decision about what to have for lunch and explain that you will eat in the dining room or the kitchen. Use memory aids when forgetfulness is a problem. Identify and discuss opportunities to encourage physical and mental ability.

3. Prepare the individual for changes that can be anticipated. For example, a move to a new home, a trip to the doctor, etc.

4. Emphasize good nutrition. Explain how you would do this.

5. Keep the individual safe. Be aware of potential dangers such as wandering, misuse and mishandling of stoves and other electrical appliances. Discuss potential dangers with others in the group.

6. Identify changes which may implicate complications; behavioral changes such as depression, agitation aggression, incontinence.

7. Obtain information from the primary care provider about the nature and diagnosis, extent of the impairment, and the prognosis.

8. Discuss how you can utilize community social service and social supports such as health care resources, respite care, day health centers, homemakers and home health aides, and friendly visitor programs.

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